

GENETICS

Informed choice of pregnant women in prenatal screening tests for Down's syndrome

H-H Chiang, Y-M (Yu) Chao, Y-S Yuh

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See end of article for authors' affiliations

Correspondence to: Hsien-Hsien Chiang, Associate professor, Faculty of Nursing, National Yang-Ming University, No 155, Sec 2, Lih-Nong St, Taipei (112), Taiwan, ROC; hhchiang@ym.edu.tw

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Background: Although maternal serum screening (MSS) for Down's syndrome has become routinely available in most obstetric clinics in many countries, few studies have addressed the reasons why women agree to undergo the MSS test.

Objectives: The aims of this study were to describe the circumstances in which MSS was offered to pregnant women and their reasons for undertaking it.

Methods: Participant observation and in depth interviews were used in this study; specifically, the experiences of women who had a positive result for MSS and who then followed this up with amniocentesis were examined. The interviewees were twenty six mothers aged between 22 and 35 years. The interviews were audio taped and transcribed for analysis. The results were analysed by the constant comparative method.

Results: This study identified the reasons on which pregnant women appeared to base their decisions when undergoing MSS. The reasons were first, the recognition that the procedure was a prenatal routine procedure; second, the need to avoid the risk of giving birth to a baby with Down's syndrome, and third, a trust in modern technology and in the professional authorities.

Conclusions: This study offers insights into the informed choice made by women with a positive MSS result. The reasons for undergoing MSS might help health professionals and policy makers to reflect on their practice and this may, in turn, improve the quality of prenatal care during MSS.

As genetic technology has progressed, health professionals have been able to identify the contribution that genetics makes to many diseases and to diagnose these conditions through non-invasive analysis via a simple blood test. As a result of this technological progress, maternal serum screening (MSS) for Down's syndrome, now supplied by a number of biochemical companies, has been routinely performed in Western countries since the 1980s.¹⁻⁶ In Taiwan, Down's syndrome is the most common chromosomal abnormality and had a crude birth rate of 6.58 per 10,000 live births.⁷ It has been recognised as a serious abnormality and involves mental impairment as well as the risk of other birth defects. To prevent the birth of a child who suffers from mental impairment, pregnant women younger than 35 have been informed about and offered MSS for Down's syndrome as an optional part of their early prenatal care in Taiwan since 1994.⁷ Analysing the experiences of pregnant women undergoing MSS would provide a reference point for the introduction of other prenatal genetic tests at this time when so many health professionals and members of the public are greatly interested in the possibility of genetic intervention to improve health.

The aim of MSS is the identification of a subgroup at high risk of giving birth to a baby with Down's syndrome, and, for this group, a prenatal diagnostic amniocentesis test is available. The uptake of MSS, requiring a maternal blood sample between 15th and 20th weeks of gestational age, varies from hospital to hospital and ranges from about 50% to 80% in Taiwan.⁸ The variation in uptake may be influenced by the information given before the test, by the way it is given, or by the knowledge and attitudes of the person who offers it.⁹ In Taiwan, MSS is not covered by general health insurance. The commercial availability of MSS has meant, however, that it has rapidly become accepted as a part of routine prenatal care. As a consequence, the crude live birth rate of Down's syndrome babies decreased from 5.45 per

10,000 in 1993-1994 to 1.75 per 10,000 after 1996.⁷ It thus seems that the "preventive function" of MSS has worked in Taiwan.

Maternal serum screening is mainly performed to identify a fetus that, because of Down's syndrome, is considered undesirable by parents, health providers, and society in general. Few women have the confidence to decline serum screening because they do not understand its rationale and its implication. Nonetheless, women have to make several important decisions in a limited time—between the 15th and 20th week of gestational age of the fetus when the screening can be done—because the detection rate of MSS for Down's syndrome pregnancies is 60-80 per cent with a five per cent false positive rate.^{8 10 11} At the maternal serum α -fetoprotein level commonly used for identification of pregnancies at risk, the calculated risk is 1:270, which correlates with the risk at age 35. Abnormal values are followed by ultrasound to confirm dating. If dating is correct, amniocentesis is offered for definitive testing for chromosome abnormalities.

Therefore, the procedure of prenatal genetic screening and diagnosis using MSS, ultrasound, and amniocentesis has the potential to both allay anxiety and to create anxiety.^{5 12-14}

Health professionals need to understand how women make such an informed decision so that they can improve communication during the prenatal counselling process and decrease the negative effects caused by the test, thus improving the care women receive prenatally. In order to shed light on how clients' decisions are shaped, we need to observe the specific processes involved in MSS, examine the women's understanding of the test, and identify their reasons for accepting it. The aims of this study were to describe the decisions involved in undergoing MSS from the perspective of the pregnant woman.

Abbreviation: MSS, maternal serum screening

METHOD

Sample

A convenience sample of 26 pregnant women was selected from the waiting room for amniocentesis in a teaching hospital in Taipei, Taiwan. All women attend a dating scan at the hospital or private clinic at 10 to 12 weeks of gestation. At this visit, women also see an obstetrician for a routine care, which might well include a blood test; at the same time there is an opportunity to talk to a nursing counsellor. Further blood is taken for a Down's syndrome screening (MSS) at the following visit—that is, at around 15 or 16 weeks of gestation. Abnormal values are followed by ultrasound to confirm dating. If dating is correct, amniocentesis is offered for definitive testing for chromosome abnormalities. The criteria for inclusion in this study were willingness to participate and a positive screening from MSS. Approval to conduct the study was given by the hospital's ethics committee.

Data collection and analysis

Data were collected by means of participant observation and face to face, in depth interviews. The interviews were all conducted by the first author and were organised around the experiences of pregnant women undergoing MSS. Pregnant women were asked the following question: "How did you decide to undergo MSS?" and invited to discuss the way they made decisions concerning MSS by appropriate follow up and probing questions as needed. These included the way they were informed of the result of their MSS, their experiences and comments, and how they felt about the delivery of MSS during prenatal care. The interview was flexible and it was extended and altered as the interview progressed and themes emerged.

With respondents' permission, each interview was tape recorded; each took between 40 and 80 minutes to complete. After each interview, the tape was transcribed; in addition, copious field notes were taken. After the interview, the notes were expanded as promptly as possible and the audiotapes were transcribed verbatim within 48 hours.

The data collection and analysis were qualitative in style, with an approach known as grounded theory. Using this approach, we coded our emerging data as we collected it. Through coding, we started to define and categorise our data. The general rule in grounded theory research is to sample until theoretical saturation of each category is reached—that is, to refine the ideas, not to increase the size of the original sample.^{15 16} The interviews continued until emerging categories had been saturated and no new information was being obtained in any respect of informed decision. The line by line coding gave us insight into what people were doing and what was happening in the setting. When comparing and selecting codes, we found similar statements and concerns about informed choice. Through comparative methods, we specified the conditions under which they were linked to three categories of informed choice: routine, risk, and trust.

RESULTS

The circumstances in which maternal serum screening was offered

At time of offering, the screening test had usually been introduced by a nurse at the obstetric outpatient department who had provided the patient with a leaflet. Written informed consent was obtained at the physician visit. The cost of MSS ranges from US\$10 to US\$30 depending on the patient's citizenship and hospital policy, but is not covered by health insurance.

Originally, the primary participants for this study were pregnant women who had had MSS at a clinic and in particular those who had had positive results and had

proceeded to have amniocentesis. All 26 women interviewed were asked to describe the time when serum screening was offered to them. The age of the subjects ranged from 22 to 35 years old (mean = 30); all women had fewer than two children and a maximum of three previous pregnancies (Table 1). Most (24/26) of those interviewed were born in Taiwan, and the remaining two had come to Taiwan after their marriage. In terms of religion, 42.3% were Buddhist, 19.2% were Taoist, and 3.8% were Christian. More than half (53.8%) had an undergraduate degree and 11.5% had a graduate degree. Only one person who was interviewed had not completed high school. Most of the couples (20/26) did not live with their parents. For almost half (14/26) of the subjects, this was the first time that they had received MSS.

The women received the information of a positive result for maternal serum screening two to fourteen days after the blood sample was taken (mean = 6.6 days). Fifty per cent of women with positive MSS findings were informed by telephone from hospital or clinic whereas 30.8% (10/26) of the subjects with positive findings were informed by a physician at a following visit (Table 2). The women underwent amniocentesis within two weeks (mean = 6.5 days) after they were informed of the positive result.

Reasons for deciding to undergo the maternal serum screening

Recognising MSS as a prenatal routine care procedure

Pregnant women who underwent MSS as part of routine prenatal care tended to take it without really considering its implications. They usually did not pay attention to the real meaning of it until the positive test result was presented to them.

Although MSS was presented as a voluntary choice, the decision seemed to be imposed by the prenatal care system. When we posed the question: "How did you decide to have the test?" one pregnant woman answered: "I thought it was a routine test during pregnancy. It cannot be called a decision. It just definitely should be done." Another woman gave a detailed description: "When we went to the prenatal clinic the first time, the nurses informed us of the time schedule for the prenatal examination. MSS was just one of the tests that were part of maternity care." It seems that MSS has been generally assumed to be an acceptable part of

Table 1 Demographic data for the pregnant women (n = 26)

Pregnant women	n (%)	M ± SD
Age		30 ± 2.89
22–29	8 (30.8)	
30–34	18 (69.2)	
Number of children		0.62 ± 0.64
None	12 (46.2)	
One	12 (46.2)	
Two	2 (7.7)	
Education		
Elementary	1 (3.8)	
High school	8 (30.8)	
College	14 (53.8)	
Master	3 (11.5)	
Religion		
Buddhism	11 (42.3)	
Taoism	5 (19.2)	
Christianity	1 (3.8)	
Others	2 (7.7)	
None	7 (26.9)	
Family		
Nuclear	20 (76.9)	
Extended	6 (23.1)	

Table 2 The women's experiences when undergoing MSS testing (n = 26)

	n	%
Frequency of MSS		
Four times	1	3.9%
Three times	2	7.7%
Two times	9	34.6%
Once	14	53.8%
Location of MSS testing		
Private clinic	8	30.8%
Local hospital	10	38.5%
Medical centre	8	30.8%
Method by which patients were informed of the result		
Informed by following visit	8	30.8%
Informed by the phone	13	50.0%
Patients called the clinic	2	7.7%
Not mentioned	3	11.5%

routine visits to most pregnant women. Actually, patients should be billed for MSS because it is not like the other routine blood tests in prenatal care that are billed to general health insurance.

Because the delivery process of MSS is formulated as routine, informed choice may be overlooked. A woman gave this comment: "The examining process made you feel that the test is a necessary part of maternity care". This routine test is acceptable to most pregnant women until something goes wrong. Initially, the women may look on MSS as a simple blood test and not pay much attention to it. One woman reflected on her former pregnancy: "At my first pregnancy, I did not notice that I had this test. But, this time, I was much more worried (about having a positive result for MSS)."

Although we all understand that a woman's decision whether or not to receive prenatal screening test should be an informed one, we found that little information was provided about the test by the health professionals.¹⁷ The entire healthcare delivery system in Taiwan seems to simply present MSS as a routine procedure, and to be completely blind to the possibility that it could be anything other than routine. Instead, the system seems to shun the humanity of the person involved, not even considering the issue of obtaining their informed consent as an essential part of the process of offering MSS. Since the importance of human dignity is still undervalued because of the influence of traditional paternalism in general society as a whole and in the healthcare system in particular, unnecessary anxieties following the false positive results were common. An effort to raise the awareness of the importance of human rights and of a person centred care approach among health professionals by means of providing detailed information on MSS to the pregnant women before they make any decision about having MSS is strongly recommended.

Avoiding the risk of giving birth to a Down's syndrome baby

The prospective parents expressed enthusiasm about the health and normalcy of their unborn child and the reasons given for not having a child with Down's syndrome, including that it was good for the parents and good for the child.

A woman stated her perspective on having a baby with Down's syndrome: "No one wants to have a baby with problems. It is a burden to all of us and takes lots of physical energy and social resources". This parent centred attitude did not arise only from economic concerns, but also from concerns about the social and psychological impact of having

a Down's syndrome child. Another woman said: "Having an unhealthy baby will have a great impact on your life. No one wants to take the risk. It may totally change your life."

From the perspective of being good for the child, one parent addressed this question: "If we are getting old, who will take care of the child? Will he or she become a burden on others?"

The good of the parent as well as the good of the child in women's decision to undergo MSS was clearly manifested in their concern about the burden of having a child with Down's syndrome. Choosing to avoid the risk might reflect social and health policy in Taiwan, which seems to imply that the life of a child with Down's syndrome is troublesome and not worth living.

Trust in modern technology and the professional authorities

The fact that the pregnant women accepted MSS unquestioningly seemed to indicate that women in Taiwan not only tend to be submissive to the professional authorities but also to hand over their trust, hope, and confidence easily to the unspecified power of the authorities. One woman said: "I was so lucky to have a positive MSS test result. Then I knew I could have the follow up amniocentesis to make sure of the fetus's condition." This trust came from belief in scientific technology. This woman further commented: "Medical tests today are scientific, and of course we will be safer if we receive the test". Her trust led the woman to perceive MSS as a very helpful technology that ensured the baby's health.

This trust was sometimes replaced with a subtle feeling, at the time of undergoing MSS, of a powerlessness when facing the professional authorities. The powerlessness encountered in decision making about MSS led pregnant women to hand themselves over to the hospital staff. This feeling was revealed again when the test result did not coincide with their expectations that the test would ensure the baby's health. Yet another woman said: "We are powerless when we encounter medical science. The only thing we can do is to trust the doctor. If the doctor just told you to have the blood test, it was impossible to reject it."

Pregnant women feel unsure and alienated from medical knowledge and medical professionalism. Trust is a crucial component of health professionalism.¹⁸ To be trusted, medicine must do an adequate job of policing itself in order to prevent pregnant women from suffering unnecessary anxiety.

DISCUSSION

This study showed that even if maternal serum screening is presented as a voluntary choice, the decision seemed to be imposed by the health delivery system and constructed social values. Jennings stated that two external forces constrained individual values, desires, and conscience in decision making. One is the coercive power of society, including laws, incentive systems, and rewards. The other is the influence of cultural and belief systems, including the norms of religion, custom, and tradition, and the pressure to conform to the behaviour of others.¹⁹ In this study, recognising MSS as routine care and trusting in medical authority reflected the impact of the health delivery system on the pregnant women. A study in California showed that not only medical/legal and institutional forces affect the use of MSS, but providers also shape women's understanding of the meaning and purpose of MSS.²⁰ Gekas, Gondry, Mazur *et al.*,¹ surveyed pregnant women who had amniocentesis after a positive screening result and were able to show that MSS was imposed as mandatory by 41.5 per cent of providers and done without the patients' agreement in 16 per cent of cases. In Taiwanese studies, women had a poor understanding of MSS when it

became a routine component of prenatal care.^{21–23} Besides, social and family contexts for making decisions on prenatal testing differ among racial/ethnic groups. Asian women seem to be far less likely than other racial/ethnic groups to regard a child with Down's syndrome as acceptable in their community.²⁴ It is not easy for pregnant women to make authentic autonomous decisions in the face of such a medical and social value system.

Prenatal genetic testing provides options for women to control the pregnancy process; however, the practice has constructed a value whereby some kinds of life are seen as worth living and others are not. This is because there is no available treatment for most detectable conditions and abortion is generally the only available intervention in the event of a positive diagnosis. This raises the question of what kind of life is worth living and who has the power to decide.²⁵ Social attitudes and practice regarding prenatal testing for Down's syndrome illustrate the bad side of eugenics—that is, a deep seated ableism on the part of society's leaders, who have benefited by the abilities they currently enjoy.²⁶ This is problematic for society because social and cultural preoccupations may influence pregnant women's willingness to appreciate the many forms of human variation.

For some women, MSS results in an inner "anticipating decision regret".¹¹ Trying to avoid future regret leads to a situation where the pregnant woman may wonder if the decision is right no matter what decision is made.¹⁴ Therefore, despite the fact that women are provided with only a little information about the test and its purpose, most of them accept it.

Trust in health professionals and technology is transformed into a specific reassurance when there is a normal test result.²⁷ Our interviews showed that trust is not only transformed into reassurance but also comes from an internal powerlessness in the face of medical authority and technology. Sometimes, women are more concerned with pleasing the nurse or the physician than in participating in a decision about their care.²⁸ It is sometimes easy to give up one's selfhood after a decision that has not turned out well.²⁹ Some women, however, decline the test because they oppose abortion, have a lack of trust in the test, or are confident in their ability to bear healthy children.²⁷ This ability to say "No" might be the turning point whereby one gains a consciousness of being oneself. This negation plays an important part in a moral life.²⁹ The moral life consists not only in learning to cope with suffering as an authentic self, but also, in this circumstance, in exercising the right of the authentic self not to undergo MSS.

In order to empower pregnant women undergoing MSS, healthcare professionals should consider how they can improve prenatal care. First, healthcare professionals should carefully reflect on their own values and how they deliver care in the context of a trust based relationship. This is essential where some form of new genetic technology is involved, which, together with the needs of professionals and society, might result in a burden on the patient.³⁰ If the patient is not well informed, MSS causes unnecessary anxiety to women when they are informed about a positive result.^{31, 32} Second, a pregnant woman's understanding of it being quite possible both to want to give birth to, and to value and believe in a child with Down's syndrome, should be facilitated earlier, before she is approached about MSS. Although our study provides an understanding of how women make their informed choice during prenatal genetic screening, we still need to define how the women cope with bad news and how the healthcare system delivers MSS, in order to help such women. At this time, when there is great interest among both health professionals and the general public in using genetic intervention to improve health,

women undergoing prenatal genetic screening need to be supported so that they can think more deliberately about the possible impact of such a test, rather than just being given information and left alone to make a decision.

CONCLUSION

There is a consensus in Taiwan that undergoing maternal serum screening should be the result of an informed choice. In this study, the authors have shown that the reality of informed choice is more complex than they expected. Choice is not necessarily a rational decision process based on weighing risks and benefits and consideration of alternatives. As health professionals, we live with the myth of "informed consent" and we often fail to see how clients actually make their choices. This study attempts to break down this myth through learning about the perspectives of pregnant women undergoing MSS.

This study addresses the reasons why pregnant women undergo MSS and discusses some of the ethical issues that are part of informed decision making in prenatal diagnosis. These issues deserve careful reflection by health professionals. As health professionals, we need to pay more attention not only to what happens in the health delivery system and how the social value system is working in this context; we also need to facilitate selfhood so that authentic and autonomous decisions can be made. Practitioners of prenatal care should, therefore, pay much more attention to the psychosocial approach they use when giving prenatal genetic counselling to patients.

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Authors' affiliations

H-H Chiang, Faculty of Nursing, National Yang-Ming University, Taipei, Taiwan, ROC

Y-M (Yu) Chao, Center for Health Policy Research and Development, National Health Research Institutes, Taipei, Taiwan, ROC

Y-S Yuh, Department of Pediatrics, Tri-Service General Hospital, National Defense Medical Center, Taipei, Taiwan, ROC

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